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ABSTRACT

This booklet, which is designed for Colorado families with children who have physical or mental disabilities or are at risk for such disabilities, outlines six support mechanisms for these families. The mechanisms include: (1) the early identification process, which is used to locate, evaluate, and identify eligible young children; (2) case management, which ensures that the services required are actually provided; (3) the Individualized Family Service Plan (IFSP), which is developed by the family and a multidisciplinary team of health care and educational professionals; (4) public awareness, which involves informing the public about disabled or at-risk children through a centralized service and resource directory and community education programs; (5) development of responsibility by training parents, professionals, paraprofessionals, and volunteers to work with these young children and their families; and (6) assurance of accountability by providing a single line of responsibility through the Colorado Department of Education's Special Education Services Unit. This unit works with the Colorado Interagency Coordinating Council to handle concerns and complaints and to safeguard the rights of young children and their families. (MDM)

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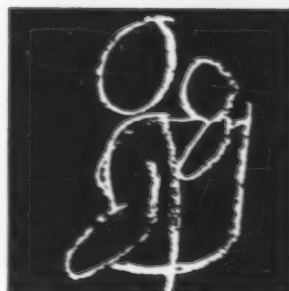
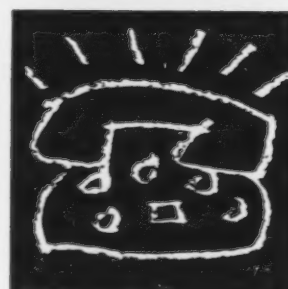
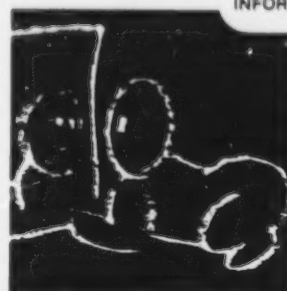
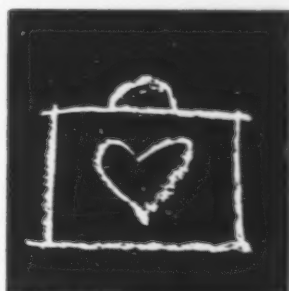
THE JOURNEY TO A DESIRABLE FUTURE

for Colorado's Young Children
and Their Families

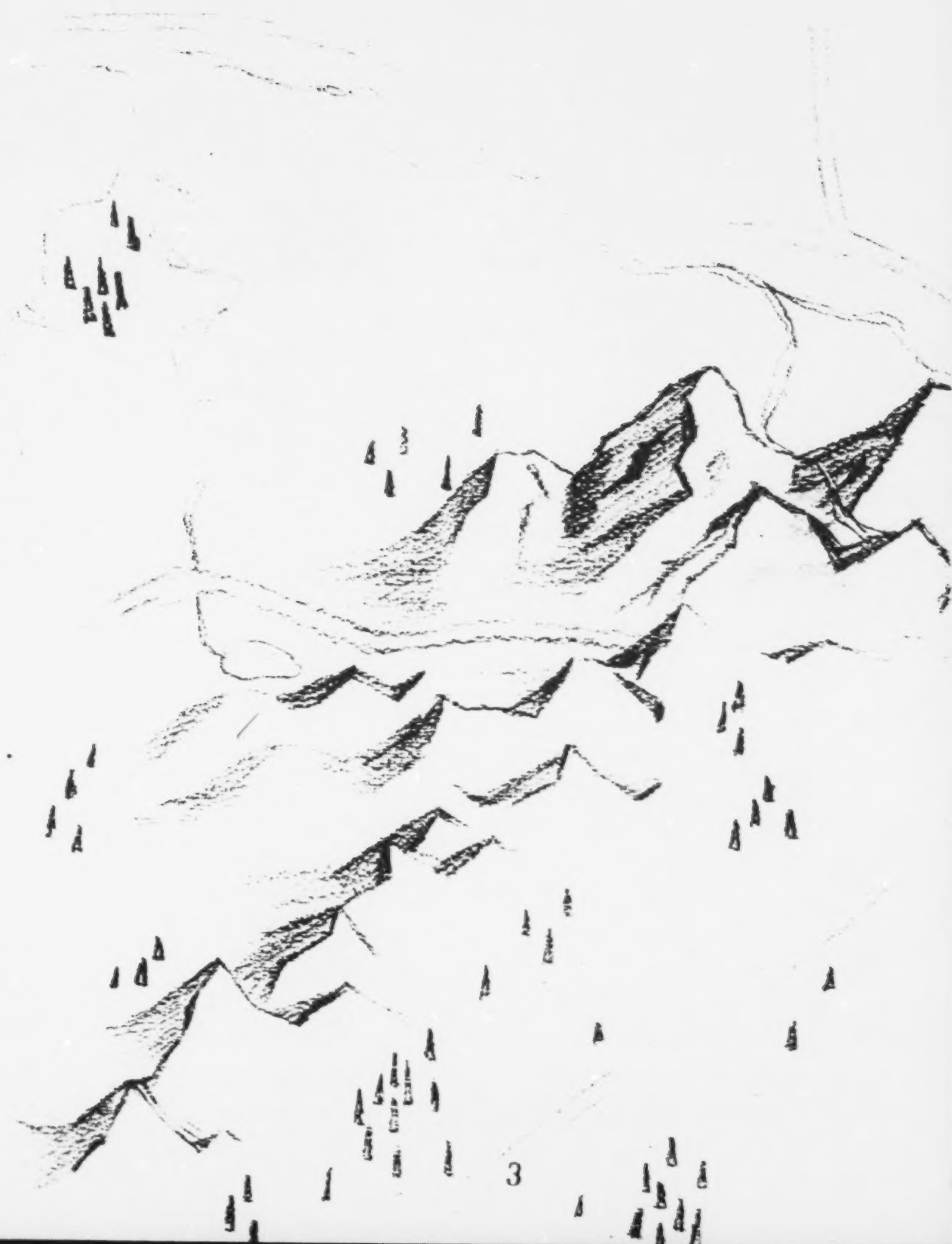
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*A Report of the Colorado Interagency Coordinating Council
to the People of Colorado*



The Journey to a Desirable Future

for Colorado's Young Children
and Their Families

Second Annual Report

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In 1975, Congress passed the Education of All Handicapped Children's Act; it required that school-aged children with special needs receive free and appropriate educational services needed to help them learn. In 1986, Congress amended that pioneering legislation. Public Law 99-457 would go an important step further, requiring states to educate children and their families from the time the children are age three, and encouraging states to develop and implement a coordinated service system for families and children from birth.

The Interagency Coordinating Council

In 1987 the Colorado Interagency Coordinating Council, a group of parents, agency representatives, physicians, specialists, and early childhood providers appointed by the Governor to guide Colorado's participation in Public Law 99-457, set out on a journey. It was a journey of challenge and discovery. It was an historic journey to change systems and to find out what happens to families within those systems. It was a journey to create desirable futures for young children with special needs and their families across the state.

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Dear Mom & Dad,

Ever since our baby was born, we've been struggling to create a full and desirable future for him. We've struggled to find out what is available as supports for him and us. We've questioned what our role as his parents should be, and we've wondered how to ensure that he is included in the community around him. There have been many heartaches and many uncertainties.

Now we're going on a journey to find that desirable future for him. Where we're going there are no maps, so we'll make our own as we go along. It truly is uncharted territory. We know it won't be easy. We know there will be hardships and barriers and times when we will get discouraged and have to retrace our steps. But we're determined to go forward. There's no turning back now!

Preparing for the Journey

VALUES TO GUIDE THE WAY



The Interagency Coordinating Council spent its first year planning and preparing for the journey ahead for Colorado families. The Council developed value statements to guide and direct each step of the way. These statements said that Colorado's service system should be designed to ensure access to supports for all children with special needs and their families.

The Interagency Coordinating Council values stated that the service system should:

- View the competencies of children and families rather than focusing on their weaknesses and deficits.
- Focus on the needs for the child within the context of the family.
- Recognize parents as active and equal partners in making decisions.
- Provide choices and options of services.
- Use existing resources in creative and flexible ways that allow for differences in individual communities.
- Provide adequate funding for what is required.

DECIDING WHO SHALL GO

Before the journey could begin, the Interagency Coordinating Council needed to decide the infants and toddlers (birth through two years of age) and their families who would be eligible for services under the infant-toddler portion of the new law, and to determine how to evaluate and assess children and families in the most sensitive and appropriate manner.

The Council determined that children who would be eligible for publicly supported services would be:

- Children at risk for having developmental delays,
- Children with medical conditions that are associated with developmental delays, and
- Children with significant delays in at least one or more areas of development.

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Children at risk for developmental delays were defined by the Council as those children whose parent(s) have developmental disabilities.

When it decided on this definition, the Council was aware that other children are also at risk for developmental delays because of such factors as poverty, teen pregnancy, chronic illnesses, and so on. The Council has committed to study other at-risk groups of children, and to consider whether the definition of children "at-risk" should be expanded in the future. The Council is also working closely with other agencies and organizations in Colorado that have a mission to assist children at risk.

Children with conditions associated with significant developmental delays were defined as children from birth through two years who have conditions known to have a high probability of resulting in significant developmental problems, but who may not show signs of delayed development at the time of diagnosis. These conditions are:

- Chromosomal syndromes and conditions associated with mental retardation.
- Congenital syndromes and conditions associated with delays in development.
- Sensory impairments.
- Metabolic disorders.
- Prenatal and perinatal infections and significant medical problems.
- Low birth weight babies weighing less than 1,000 grams.
- Problems acquired after birth and known to result in significant developmental delays.

Children with significant developmental delays were defined by the Council as those who have been diagnosed by a multidisciplinary team as having a significant delay in at least one or more of the following areas of development: cognition, speech/language, physical/motor, vision, hearing, psychosocial, and self-help skills.

To establish eligibility, the Council has decided that a multidisciplinary team, which will include the family, will determine that a child has a developmental delay if:

- Evidence is available to determine a significant delay. Verification by the team should include a developmental history and at least one other assessment procedure. Other procedures may include parent reports, language sample, play-based assessments, criterion-referenced instruments, and developmental checklists.
- In addition, there must be evidence of a significant delay in development in one or more areas as demonstrated on an appropriate diagnostic assessment administered by a trained person.

Supports for Families on the Journey

Families have different needs, different problems, different dreams. Communities are different, also; what might work in one might not work in another. The Interagency Coordinating Council felt that one way of finding out what supports are most helpful for families would be to try different approaches in individual communities. The Council asked communities to plan new approaches that would follow the Council's values in the areas of early identification, case management, and the Individualized Family Services Plan.

The projects supported by the Council were the focus of this second year of planning. The projects went on "journeys" of their own. They started — and stopped. They encountered difficult times, and found other pathways that were easier. Sometimes they had to backtrack and detour. But always they were learning important lessons that will help guide the development of future supports.

THE FIRST SUPPORT: The Early Identification Process



Dear Mom & Dad,
We're finally on the road! We spent a lot of time talking about where we were going, and figuring out what we should take along and what we should leave behind. But at long last, we are underway.

As we travel, we peer eagerly ahead for the supports for families that are being developed and that promise to ease our journey and speed us to our destination. Our excitement mounts each day.

The Council determined that all families should have certain basic assurances. These are if their child has a problem: 1) it will be discovered early; and 2) that they will be connected with the services they desire to support their child and family. Everyone who is involved with young children should be aware of early identification — all parents, grandparents, child care workers, and providers who work with children and family.

“*The people who work with Jenny must understand our family's values and priorities. They need to come to our home and get to know all of us — my husband and our children, not just Jenny and me. At the same time I have some concerns about privacy. It's very wearing to have a lot of professionals in and out of your house all the time. Professionals have to be very sensitive to respecting our privacy.***”**

— Jenny's mother, Steamboat Springs

“*When I was a child, I was misdiagnosed and tracked into non-success programs. My counselors told me I would never make it in an academic program, but I managed to finish college. I worry that Pelonne will be mistakenly stuck in a slow-learner program and told he has no future. It's important that early identification also be accurate identification.***”**

— Pelonne's father, metropolitan Denver

The Interagency Coordinating Council determined that Colorado will offer child identification services that will be easily accessible and sensitive to the ethnic, cultural, and economic differences of families. The process will be community-directed, and will involve an interagency effort to locate, evaluate, and identify young children who are eligible for services. Many different child identification approaches and settings will be used.

The child identification system will include:

- An active, ongoing process using multiple resources to locate very young children suspected of having developmental delays or of being at risk for delays.
- A system to link infants and toddlers and their families with both formal and informal community resources.
- A system that is easily accessible because it has multiple entry points that are available throughout the year.

Colorado will ensure that a timely and comprehensive evaluation by a multidisciplinary team, which includes the parents, will be available for each child whose family wishes it and who may be eligible for the statewide services and supports. These evaluations will state the strengths and needs of the child and the family. They are intended to determine if the child is eligible for services, to understand the capacities of the child, and to help plan for supports. Parents and other significant family members will be actively involved in the assessment process, and evaluations will be sensitive to cultural and ethnic differences.

What People Learned about Early Intervention

“Our project has been successful in getting referrals of newly-identified infants by being respectful of the physicians’ role. When a child is identified as having special needs at birth, the physicians are asked to talk to the parents and get their written consent to be approached by the staff of our project. The physicians also provide the project with a written summary of the family’s concerns. We hope this will encourage communication between families, physicians, and the project.”

— Coordinator, Grand Junction

“Everyone warned us that health providers would resist referring infants with special needs to our program. Instead, we have had incredible cooperation from the medical community. We felt it was critical to involve physicians and nurses because they are the professionals who most often see children from birth to age 3. So I visited every physician in the area to explain why their involvement was important and why they should care about early intervention. I also went to the county nurses, who were eager to be involved.

“At the hospital, I went through channels. First I explained the project to the administrator and got his approval. Then I went to the perinatal committee of physicians who deliver babies, then to the OB nursing supervisor, and finally directly to the OB nurses. We involved them all — along with educators — in helping us to develop a criteria for identifying high-risk newborns who should be referred to our program. That involvement helped get them all invested in the process.”

— Nurse, Alamosa

“It’s essential to get an interagency group together to map out services in the community and identify where services are missing. But it’s not always easy. Some people are resistant to change and to interagency efforts. You have to be willing to take small steps. You have to build on any interagency effort that has already started. You may have to give someone an idea 10 times, and have them say ‘no.’ Then, on the eleventh try, you may find they find they claim it as their own.”

— Educator, metropolitan Denver

THE SECOND SUPPORT: Case Management



Dear Mom & Dad,
The way has been rougher than we expected. First we encountered flood-swollen streams that blocked our way, then rocky ground that slowed our progress. Fortunately, case management support was there when we most needed it. It was more help to us than words can tell, helping us to find the services we wanted for our child, and helping to hearten, encourage, and empower us. We see huge mountains ahead, but we are strong of heart and determined to find a way across them. Come what may, we will forge on.

“The most important thing for our family is to have someone help us find out about resources for Tommy. We want to know what’s available and what our options are. We want knowledge and information about services and systems. Then we’ll decide what is best for our family. We’re the ones who know our child and our family best. Professionals come and go, but we will be there for him all his life.”

– Tommy’s father, Canon City

“I really don’t like the term ‘case management’ or ‘case manager.’ My family is not a ‘case,’ and we don’t want to be ‘managed.’ We like to think of our case manager as a consultant, or a person who helps facilitate what we want to have happen.”

– Sandra’s father, Glenwood Springs

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“ When Nancy was born with Down syndrome, another family came to visit us in the hospital. They talked to us about their experience with their child and helped us know what to expect. They'd been in the same situation and they really understood what we were feeling. Later on, they were an invaluable source of information about babysitters and swim programs and all the other things we wanted for her. **”**

– Nancy's mother, Estes Park

“ If your family's basic needs aren't met, you can't be fully 'there' for your child. When I'm worried about whether I can pay the rent or how I'm going to feed Lydia, I don't have the energy to deal with therapies. I feel badly about it, but I just can't handle one more thing. That's when I really need someone to help with decisions and information. **”**

– Lydia's mother, Denver

The Interagency Coordinating Council's value is that case management will be available for all eligible infants and toddlers in Colorado. Case managers will:

- Help families gain access to the services that have been identified in the Individualized Family Service Plan.
- Ensure that services are delivered in a timely manner to families who wish to have them.
- Continuously seek services and supports that are desired by families and that will benefit the development of each child and family.
- Assist families to be involved in the development, review, and evaluation of the Individualized Family Service Plan.
- Help families develop transitional plans to preschool services when appropriate.

What People Learned about Case Management

“We had a situation recently where a baby was about to be sent home on a heart monitor, and the family didn’t have electricity — it had been turned off because the parents couldn’t pay the bill. The process for the case manager of identifying family needs with them starts very early and continues on. It’s a process of recognizing family strengths and not being judgemental about family situations.”

— Social worker, Grand County

“We found that many parents, especially those with young babies, don’t want to take on the entire job of case management alone. Instead, many prefer to be co-case managers with someone who knows the resources. The trouble is that many traditional case managers have such a heavy work load they don’t have time to seek out resources or impart information. We believe one part of the solution is for parents to become resources for their children. We must give them a general working familiarity with the system and empower them with knowledge.”

— Coordinator, statewide project

“Another part of the solution is to make better use of informal systems — others who work with and care about young children. There’s a difference in role and function between a case manager and case management. Maybe not everyone could be an effective case manager, with all the complexities that implies. But anyone can do case management activities, from Uncle Harry to a physical therapist to a nurse — anyone who cares about young children and families. We need to train all these people, as well as parents, to help fill the gaps in the formal case management system.”

— Educator, Morgan County

“We use Family Visitors to help make parents aware of services. These Family Visitors are all parents themselves, some with children with special needs. Their role is somewhere between professional case managers and people in other professions who do some case management, such as public health nurses and therapists. They have affirmed for us that parent-to-parent interactions really work. Many parents feel more comfortable talking with other parents than a professional.”

— Speech therapist, Mesa County

“Recently a family in my practice had a baby born with Down syndrome. I went in to talk with them about the diagnosis and their feelings. Ten years ago, we would have thought we needed to rush into services with a group of professionals starting to work with the child at home. At the end of my conversation with the parents, they said what would be useful would be to have another parent come see them at home to help them decide what services they want for their child. They chose the parent of a child with handicapping conditions. It's much less intrusive and is more the comforting kind of system.”

— Pediatrician, Grand Junction

THE THIRD SUPPORT:
The Individualized Family
Service Plan (IFSP)



“We want to be actively involved in the planning process as equal partners with professionals. We want help, but we want to be in charge — the ones with the final say as to what happens. The goals for Jimmy should be our family’s goals, not goals developed by a professional who may or may not know our hopes and problems and dreams.”

— Jimmy’s father, Brighton

“Any plan for Laura should help us understand what the options are for supports and services. It also needs to be reviewed often enough that it’s current. If it’s out of date, what good can it do for us?”

— Laura’s mother, Canon City

Each family wishing to have services for their eligible child will be encouraged to participate in developing an Individualized Family Service Plan (IFSP). The IFSP is a plan developed by the family and a multidisciplinary team, as well as any other persons the family wishes to include. It states the capacities of the child and family and the resources in the community to help the family meet their dreams. The IFSP process will be flexible, family-focused, and non-intrusive. It will be a dynamic, ongoing process. It will be revised at least twice a year so that it effectively meets the changing needs of the child and the family.

The IFSP process will emphasize that the child is a part of a whole — the family — which will receive the early intervention services. Families will differ in their needs and uses of publicly supported services, and in the nature and intensity of their involvement.

What People Learned about the IFSP

“There is an exciting spirit in the new law that families have a different role now. They really are at the center, and the power dynamic is shifting on who's in charge. And there is also this sense of non-intrusiveness, that when a family has a new child, they may not be ready for big teams and a big process.”

— Administrator, Denver

“It's important to find out what families want and need, and for the system to be flexible so varied needs can be met. My survey of families found that almost one-third want the IFSP meeting to be held in their homes, where the setting is more comfortable and it is easier for family members to attend. Other families prefer a meeting elsewhere. It shows that families are different, and have different needs and interests.”

— Coordinator, statewide project

“The IFSP is not just a form. It's a process to link resources and supports in the community to young children and families. It helps families identify natural supports in the community, such as child care centers and places of worship. It links families to professionals who have special skills. It helps everyone involved coordinate their efforts, and it supports the family in meeting the challenges of daily life.”

— Family therapist, Denver

THE FOURTH SUPPORT: Letting Others Know



“It’s important to help others understand the challenges faced by families with a child who has developmental disabilities. When I take Paul to the store, people stare and want to ask what’s wrong with him. Sometimes they’ll pull their children away and tell them not to stare at him. They don’t mean to be hurtful — they just don’t understand and are afraid of anything different. If our children are going to be accepted fully into society, we have to start breaking down these barriers.”

— Paul’s mother, Denver

Colorado will have a centralized service and resource directory available for families. It will develop and implement an ongoing, grassroots public awareness campaign. Campaign goals will be to:

- Implement a statewide system of services and supports for families.
- Help families connect with services and supports for families.
- Provide parents, professionals, policy-makers, and members of the public with an explanation of families’ rights under PL 99-456.
- Reach all ethnic and socioeconomic groups.
- Develop a strategy to effectively reach persons who cannot read.
- Encourage understanding among policy-makers of the importance of investing in all of Colorado’s children.
- Sensitize the public to the value of including all children — including those with special needs — in community settings.
- Celebrate differences among children and adults.

Public information will be disseminated in a wide range of settings, including places of worship; libraries and museums; well baby clinics; child care homes and centers; preschools, schools, and Head Start centers; hospitals; community centers; grocery stores; parent support groups; advocacy groups; teen parenting programs; Planned Parenthood; nutrition programs; United Way agencies; migrant health centers; parent-teacher and other organizations; and the print and electronic media.

What People Learned about Public Awareness

“Public awareness is the key to the success of any program. Talk up your project to service clubs, parent groups, professional organizations — wherever you can find an ear. When our project first began, we called the radio stations and local newspaper to explain it to them. The radio stations did interviews and the paper ran an article. After that, I sent press releases that always received a good reception.”

— Nurse, San Luis Valley

THE FIFTH SUPPORT: Developing Responsibility



Dear Mom & Dad,
What an exciting passage this is! We are making slow but steady progress. Some days we have difficulty finding a trail leading in the direction we want to go, and that slows us down. Many days we see an obstacle ahead — a mountain, a stream, or a cliff — that looks overwhelming, and it's hard not to think of giving up. But usually, when we reach the obstacle, we are able to conquer it. If not, we find ways to go around. Having highly trained and caring professionals to help us has been an invaluable support. So is having training ourselves so that we understand the systems and can better communicate our wants and dreams and desires to others.

“Of course, I want the most highly-trained providers helping us with Joshua. We want doctors, nurses, preschool teachers, and child care workers alert to any child who has a developmental problem. We want any professional who works with us to know the latest and most effective techniques.

“But there’s more. We want training, too. We want to know how to improve communications in our marriage and our family, and we need to know how to communicate better with professionals, too. There are so many issues where training would be helpful. For example, it could help us understand our feelings better, and could help us with practical things like insurance, legal issues, and planning for the future.”

— Joshua’s father, Canon City

Colorado will develop a personnel preparation model for professionals, para-professionals, parents, and volunteers. This will include training in individual communities, technical assistance, and identification of community resources.

Colorado will assure that health, education, and human service professionals are well trained to work with young children and their families. Training programs in colleges will emphasize how to provide family-focused services, how to identify community services, and how to help families use their skills, competencies, and informal resources.

What People Learned about Developing Responsibility

“I think an important part of training providers involves challenging them to be more creative. I never use the word ‘empowerment’ around some professionals, for example, because it threatens them. Some professionals are afraid that empowering parents means doing away with our expertise. That’s not true, of course. It just means we have to be more creative in how we relate to families. We need to work with families in new, non-traditional ways.”

— Family specialist, Grand Junction

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THE SIXTH SUPPORT: Assuring Accountability

“ *It's important for us as parents to be knowledgeable about our child and about supports and services in our community. We need information so we can make good, solid, informed decisions for Andrea. Information and an approach that takes into account our values and wishes gives us a sense of control over our lives.* **”**

— Andrea's mother, Boulder

Programs for infants and toddlers and their families will be administered in a collaborative interagency fashion. The Colorado Department of Education's Special Education Services Unit will be the lead agency to meet the requirement of PL 99-457 requiring the Governor to appoint one agency to assure a single line of responsibility.

The lead agency will ensure that services and supports for infants and toddlers and their families reflect the philosophy of the Colorado Interagency Coordinating Council — that families have the ability to identify their own needs and have access to public and private resources to meet those needs. The Department of Education will ensure that:

- Contracts will be made with local service providers.
- Reimbursement of funds to those service providers is timely.
- Interagency agreements will include the assignment of financial responsibility to appropriate agencies.

The Council will develop procedures to resolve complaints by parents and/or providers that will:

- Safeguard the rights of young children and their families.
- Use negotiation and mediation to resolve problems, rather than approaching them from an adversarial, legalistic framework.
- Ensure that the public is informed of procedures to resolve problems.
- Be locally based and utilize local resources as much as possible.
- Resolve complaints as speedily as possible.
- Ensure that services are provided during the period when a complaint is being resolved.

What People Learned About Assuring Accountability

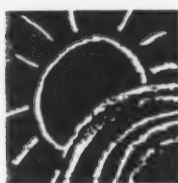
“A group of us developed a project believing that resources and support are helpful to families. But we found that not all families want to take advantage of resources and supports — at least initially. This was hard for us. We wanted families to have our services; we came with our values that said, ‘Of course you need help.’ Instead, we had to ‘butt out.’ We had to realize that what we offered was not what some families needed right then. We had to believe that families know best, and respect their decision. We constantly had to work not to be judgmental. We just check in with these families from time to time and let them know we’re available when and if they want us.”

— Project coordinator, Denver

“Interagency efforts are essential but difficult — in part because some people are dreamers and some are detail-oriented. You need both kinds of people, but it’s often hard for them to work together. The dreamers love theory and conceptualizing, but are unhappy slogging through specifics. The detail-oriented people want to get moving right away, often before the values to guide the process are fully articulated.

“Our work has confirmed that change is difficult and takes time. Some people are happy as long as we are changing other people’s programs, but not as happy when we are changing theirs. Some people are flexible and comfortable with change, while others want a course that is ‘steady as she goes.’ It has not always been a smooth road. There have been times when the road has been pretty bumpy.”

— Early childhood educator, Grand Junction



And the Journey Continues ...

Dear Mom & Dad,

It's hard to believe we've concluded the first two years of our journey. Our spirits are high, for we know we have been pioneering — leading the way into new territory that others will follow. We have been encouraged and supported along the trail by early identification, case management, Individual Family Service Plans, training for professionals and for us, and interagency coordination and cooperation. Without these supports, our passage would have been much more difficult.

Our experiences have made us into life-long advocates, mapping the way so that others who follow will find the path easier. These thoughts sustain us as we set out yet again in our search for empowerment, knowledge of systems and resources, and full partnerships with professionals.

From 1990 through 1992, the Interagency Coordinating Council will focus on replicating elements of the 1989 projects that proved effective in communities across the state. Information about these elements will be disseminated widely to parents, providers, and policy-makers. Empowering parents, connecting families with supports, and enabling them to reach for their dreams — these are the goals that the Council has set. Together, families, providers, and the Council continue on the journey to create a desirable future for all of Colorado's children.

To support families on their journey, the Interagency Coordinating Council has established a five-year timetable telling when various supports will be available. The Council determined that by 1992, a coordinated, interagency service system will be in place across the state. The early intervention services and supports will:

- Include a wide range of services, resources, and support groups.
- Be designed to meet the full range of needs of young children and their families.
- Be provided by qualified personnel.
- Conform to the individualized family service plan described in PL 99-457.
- Be provided at no cost to families except where federal or state law provides for payment; then, a schedule of sliding fees will be used.
- Be coordinated with other state, local, and community resources that provide services and supports for infants and toddlers and their families.
- Be provided under the supervision of the Colorado Department of Education.
- Be designed to meet the State standards.

“ Our dreams for Jeremy are dreams any other parent has. We want him to go to our neighborhood school and have friends and play with other kids and just be a ‘regular’ kid — whatever a ‘regular’ kid is ”

— Jeremy's father, Aurora

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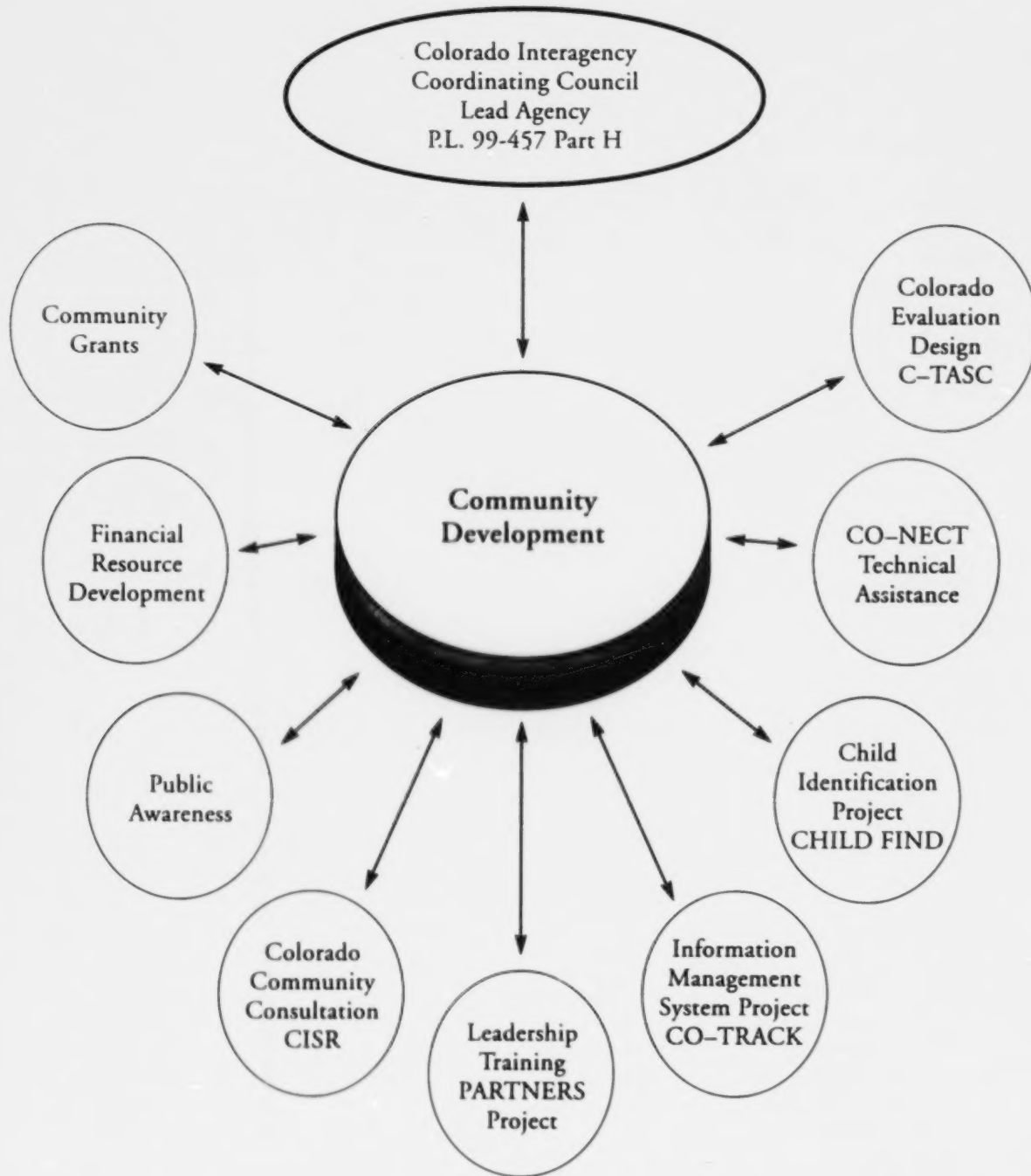
“When she is grown, I want Elizabeth to be able to have a job and to have friends and live in the community where she chooses to live — perhaps with some supports, like money management or just some help with housework-type chores. Ultimately, I’d like to see her making her own decisions about supports and services, and gradually fade me out of the process.”

— Elizabeth’s mother, Denver

“Even if Rigo never walks, I see him with a fine mind, going through high school and eventually being able to earn his own keep. I see him perhaps working in front of a keyboard, holding down a job and paying taxes. We want him to live in his own apartment, having a social life with others like him and others we call ‘normal.’ I want him to be his own man, and to have a shot at being a productive individual.”

— Rigo’s father, Westminster

INFANT/TODDLER & FAMILY SERVICES
STATEWIDE SUPPORT SYSTEM



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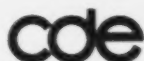
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